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How Nurses Assist Parents Regarding Life Support Decisions for Extremely Premature Infants

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Abstract

Objective—To describe nurse behaviors that assisted parents to make life support decisions for an extremely premature infant before and after the infant's birth.

Design—Qualitative, longitudinal, collective case study where interviews were done pre- and postnatally and medical chart data were collected.

Setting—Interviews were conducted face-to-face in a private room in the hospital, in the mother's home, or over the telephone.

Participants—A sample of 40 cases (40 mothers, 14 fathers, 42 physicians, 17 obstetric nurses, 6 neonatal nurses, and 6 neonatal nurse practitioners) was recruited from three hospitals that provided high risk perinatal care. Parents were at least 18 years of age, English speaking, and had participated in a prenatal discussion with a physician regarding treatment decisions for their infant due to threatened preterm delivery. Physicians and nurses were those identified by parents who had spoken to them about life support treatment decisions for the infant.

Methods—Using a semi-structured interview guide, a total of 203 interviews were conducted (137 prenatal, 51 postnatal, and 15 end-of-life). For this analysis, all coded data related to the nurse's role were analyzed and summarized.

Results—Parents and nurses both described several nurse behaviors: providing emotional support; giving information, and meeting the physical care needs of mothers, infants, and fathers. Physicians' description of the nurse behaviors focused on the way nurses provided emotional support and gave information.

Conclusions—Nurses play a critical role in assisting parents surrounding life support decisions.

Keywords

decision making; role of nurses; parent support; life support decisions

Life support decisions for infants surrounding a pregnancy with a threatened preterm delivery between 22 and 25 weeks gestation remain challenging for parents and clinicians (Batton, 2009; Chiswick, 2008). Despite the gains in survival rates of preterm infants from 1965 to 1995, the rates have not improved in the last decade (Meadow & Lantos, 2009).

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Callouts:

1. Life support decisions for infants surrounding a pregnancy with a threatened preterm delivery between 22 and 25 weeks gestation remain challenging for parents and clinicians.
2. For both parents and nurses, providing emotional support was the most commonly reported way that nurses assisted parents during decision making.
3. Parents reported that nurses played a very important role as parents were making critical decisions.

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Most of the literature on pre- and postnatal medical decision making for extremely premature infants focuses on the role of parents and physicians (Boss, Hutton, Sulpar, West, & Donohue, 2008; Payot, Gendron, Lefebvre, & Doucet, 2007; Zupancic et al., 2002). Far less is known about how nurses assist parents who are faced with life support decisions for extremely premature infants. Therefore, in this article we report our study findings related to the nurse behaviors that assisted parents to make life support decisions for their extremely premature infant. The data are from a study which examined the decision making and the decision support needs of parents regarding life support decisions made over time prenatally and postnatally for extremely premature infants from the perceptions of parents, physicians, and nurses.

Background

Types of Treatment Decisions

Life support treatment decisions involve prenatal decisions regarding pregnancy management, delivery, and immediate care of the infant, and postnatal decisions for life support for the infant, including decisions for end-of-life care. Mothers at risk for delivering between 22 and 25 weeks may have several options for medical treatment, which will differ based on the individual case, such as the exact gestational age of the infant and the condition of the mother and of the infant (Batton, 2009). Depending on the situation, parents may be asked to make decisions at each step in prenatal management, including whether to interrupt the pregnancy. Those who continue the pregnancy may be offered the choice of inpatient or outpatient treatment. If delivery does not happen to occur immediately upon admission to the hospital, and depending on the condition of the mother and baby, parents may be asked prenatally to make delivery room decisions. These decisions include the mode of delivery (Cesarean or vaginal), and the degree of resuscitative effort at birth. Postnatally, parents may be asked to make decisions about sustaining or withdrawing life support treatment.

CALLOUT 1

Nursing Involvement with Decision Making during High-Risk Perinatal Care: Pregnant women who are medically at risk (Sittner, DeFrain, & Hudson, 2005), in particular those on in-patient bed rest (Maloni & Kutil, 2000; Price et al., 2007; Richter, Parkes, & Chaw-Kant, 2007), experience a number of adverse physical and psychological effects, which have implications for their involvement in decision making. In one study, investigators found that many women reported consequences to being hospitalized, including stress, a loss of control over their pregnancy and familial obligations, boredom, and feeling burdensome for their families and health care professionals (Richter et al., 2007). In this setting, it is recommended that nurses help mothers to manage their stress by listening to and reassuring the mother that she did nothing wrong to cause the condition, by providing ongoing information about the mother's and baby's condition, and by involving parents in decision making (Stringer, Miesnik, Brown, Martz, & Macones, 2004). Other investigators described the critical role of spirituality in the women's health and healing when faced with a high-risk pregnancy (Price et al., 2007). Although women's definition and expression of their spirituality varied, all women noted the importance of spirituality in their lives and in particular the role that spirituality played in alleviating the stress associated with a high-risk pregnancy (Price et al.).

In the neonatal intensive care unit (NICU), parents rely primarily on communication with health care providers when making decisions about their child's care (Kowalski, Leef, Mackley, Spear, & Paul, 2006; Wocial, 2000). In general, parents want to know as much information as possible about their child's condition (Harrison, Kushner, Benzies, Rempel, & Kimak, 2003; Kavanaugh, Savage, Kilpatrick, Kimura, & Hershberger, 2005; McHaffie,

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Laing, Parker, & McMillan, 2001; McHaffie, Lyon, & Hume, 2001; Pector, 2004; Zupancic et al., 2002). In a study by Wocial (2000), that explored 20 parents' perceptions of their involvement with life support decisions in the NICU, parents' experience was influenced by their impressions of providers. According to Wocial, nurses and other clinicians created a context of caring for the parent's experience in the NICU. In this study, parents perceived that providers were caring when they demonstrated behaviors that showed that both the mothers and their infants were important. These behaviors included providing emotional support, spending time with parents, displaying emotions, and modifying hospital rules to allow for prolonged family presence. Creating this context of caring promoted trust between parents and health care professionals and enabled parents to be actively involved in decision making and feel confident about the decisions that were made.

In a similar study of life support decisions in the NICU, McHaffie (2001) found that parents looked primarily to providers for support in making these decisions. A majority of parents in this study identified NICU nurses or midwives as providing decision making support (McHaffie, 2001). In another study that explored how parents are given information in the NICU, investigators also found that the nurse was chosen by the parents as the person who spent the most time with the parents and was the best source of information about their baby's condition (Kowalski et al., 2006).

Similar findings regarding decisional support have been shown by other investigators who examined the role of the neonatal nurse in decision making (Monterosso et al., 2005). In this study, nurses described their role as advocates for the infant and family. Characteristics of an advocate included effective communication skills, neonatal nursing knowledge and experience, empathy and respect for the family, and assertiveness and confidence, and being a team member.

Theoretical Framework: This study was guided by the Ottawa Decision Support Framework (O'Connor, Tugwell, Wells, Elmslie, Jolly, & Hollingworth, 1998). This framework was developed for health decisions that are stimulated by a new diagnosis or circumstance and require careful deliberation because of the uncertainty or value sensitive nature of the risks and benefits. The Ottawa Decision Support framework is organized according to three phases: (a) assessing client and practitioner determinants of decisions, (b) providing decision support, and (c) evaluating quality and outcomes of decision. This study focused on the first phase of the framework, assessing determinants of decisions. Assessing determinants of decisions includes: (a) client and provider sociodemographic and clinical characteristics (e.g., age, gender, clinical diagnosis of patient); (b) perceptions of the decisions (e.g. knowledge of the health care condition; information that was given/explained and evaluation of the way it was given); (c) perceptions of important others about the decisions (e.g. individuals who are involved in making or influencing the decision, including significant others, family, and health care professionals); and (d) personal and external resources used to make the decisions (e.g. information, advice, emotional, instrumental, and financial support from others to make the decisions; skills; and advice for others).

Method: This study was descriptive, prospective, and longitudinal and used a qualitative case study approach. Collective case study is a way to examine a number of cases within a study (Stake, 1995). The goal of qualitative case study research is to seek an understanding of the case, particularly the complexity of its interactions within its contexts, as well as the interrelationships that exist among all cases. In this article, we present study findings related to the nurse behaviors that assisted parents to make life support decisions for their extremely premature infant.

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Sample and Recruitment: A sample of cases (comprised of expectant parents, physicians and RNs) was recruited from three hospitals that provided high risk perinatal care. Inclusion criteria included expectant parents at least 18 years of age who were English speaking and had participated in a prenatal discussion with a physician regarding treatment decisions for their infant due to threatened preterm delivery (22 0/7 to 25 6/7 weeks gestation). Sampling was purposive to include mothers who, at recruitment, were at varying gestational ages between 22 0/7 and 25 6/7weeks. All expectant mothers were hospitalized at the time of recruitment. Physicians who participated in this study were identified by parents as the physician (attending obstetrician, maternal-fetal medicine attending physician or fellow, or neonatal attending physician or fellow) who had spoken to them about life support treatment decisions for the infant. Nurses in this study included obstetric and neonatal staff nurses and neonatal nurse practitioners (NNPs) who were identified by parents as those who clarified (staff RNs) or provided (NNPs) information.

IRB approval was obtained at all participating sites. Recruitment occurred after a research specialist at the hospital obtained the expectant mother's written permission for the principal investigator (PI) or co-investigator (Co-I) to contact her. The PI (KK) or Co-I (TS) contacted the mother and arranged for an interview. Most of the interviews were conducted on the same day that the mother was contacted unless the mother requested that the interview be the following day. All of the initial interviews were conducted prior to the mother giving birth. Fathers were identified by the mother, and with fathers' permission, were recruited by the PI (KK) or Co-I (TS). The parents gave permission for a different study investigator (TS or TM) to conduct interviews with the physicians and nurses. This approach was done in order to maintain confidentiality, so that the same investigator never interviewed the parent(s) and health care providers on the same case. The physicians and nurses were only contacted after giving their written permission to the research specialist.

Data Collection: Three types of measures were used: interview guides, a demographic data collection form and a medical chart form (for maternal and infant medical history and documentation of discussion about life support decisions). There were four types of semi-structured interview guides (prenatal, postnatal, stillbirth, end-of-life) with different wording for the parents and health care professionals (physicians and nurses). Interview guides were based on the Ottawa Decision Support Framework as described earlier and included: (a) client and provider sociodemographic and clinical characteristics, (b) perceptions of the life support decisions, (c) perceptions of important others about the life support decisions, and (d) personal and external resources used to make the life support decisions. Life support treatment decisions were defined as prenatal decisions regarding pregnancy management, delivery, and immediate care of the infant, and postnatal decisions for life support for the infant, including the decision to withdraw life-sustaining treatment.

For this article, we present the findings related to the nurse's role in assisting parents to make life support decisions for their infants. Examples of questions from the parent interview guides that generated data related to the nurse role were: Who helped you understand the information? How did they help you to understand the information? As you think about the life support decisions you have made what stands out in your mind as helping you to make them? Examples of questions from the nurse and physician interview guides that generated data related to the nurse role were: How did you help parents to make the decision? Did you talk with other staff, such as nurses [for physician interviews] or social workers, or others involved in the care of the parents about decisions to be made?

Written, informed consents were obtained from all study participants before data were collected. The investigators (PI and Co-I) used their extensive clinical and research expertise with interviewing parents to guide them to tell their story and conduct the interview in a

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very sensitive manner (Kavanaugh, Moro, Savage, & Mehendale, 2006). All parent interviews were conducted in a private setting, were audio recorded, and lasted between 30 – 45 minutes. Mothers and fathers were offered the option of being interviewed separately. Demographic and medical chart data were collected at the end of the first interview; the medical chart data were updated after subsequent interviews. Physicians and nurses were interviewed privately in person or via the telephone for approximately 30 minutes; all interviews were audio recorded. To avoid problems with recall, physicians and nurses were interviewed as soon as possible after the parents' prenatal interview. At the end of the first interview, the interviewer completed the demographic data form. Parents and physicians were contacted by telephone weekly until 25 weeks gestation or delivery of the infant, whichever came first, to ask about changes in life support decisions. If there were changes, subsequent interviews were done.

In each case, postnatal interviews were conducted regardless of infant outcome, typically within several weeks after the infant's birth. When the infant was live born between 22 and 25 weeks gestation, mothers and physicians were also contacted weekly to ask about changes in life support decisions. If there were changes, subsequent interviews were done. These weekly contacts continued for the first 28 days of the infant's life or until two months of age if the infant was determined to be clinically unstable. Parents of stillborn infants were given the opportunity to participate in a post-birth interview to continue to tell their story, and offer any additional advice for improving care to families. When there was a neonatal death, an end-of-life interview was conducted with parents and health care professionals. For parents, these interviews were held when parents were emotionally ready, which varied from several weeks to several months after the death, and were conducted in person or by phone per parent preference. For health care professionals, these end-of-life interviews were typically conducted within several weeks after the death.

A total of 203 interviews were done. Of these interviews, 137 were prenatal, 51 were postnatal, and 15 were end of life. Medical record data were collected for each of the 40 cases.

Data Management and Analysis: All interviews were transcribed verbatim, checked for accuracy, and coded. Then, the coded interviews were entered into Atlas.ti, which is a software program designed to store and retrieve coded data. Interrater reliability was established by independent coding all of transcripts from 18 of the 40 cases (45%) by two investigators who then compared coding. Recoding occurred until the investigators' agreement was reached. After summaries of each case were generated, matrices were then constructed for each type of interview (prenatal, postnatal and end-of life), allowing for comparison of data within and across cases. Matrices displayed thematically coded data across and within parents, physicians, and nurses.

For this analysis of the nurse role, all coded data from all interviews that were related to the nurse role were reviewed. The code, nurse role, was defined as all data related to any supportive or informational care provided by nurses. Two investigators (KK and TM) independently reviewed all coded data related to the nurse code. These coded data were reviewed to identify and describe patterns in the data, noting the source of the data (parent, physician, nurse) and frequency of occurrence. The final description of the categories of nursing role was prepared after consensus was reached between the two research team members. The following sections contain a descriptive summary of the categories of the nursing role. Specific behaviors are outlined within each category.

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Results

Description of the Sample: A total of 40 cases were recruited. For these 40 cases, participants included: a total of 54 parents (40 mothers, 14 fathers); 29 nurses (17 obstetric, 6 neonatal, 6 NNP); and 42 physicians (3 obstetricians, 19 maternal-fetal medicine physicians or fellows, 20 neonatalogists or fellows). Of the 40 cases, only 21 fathers met eligibility criteria for the study. Of these 21, 14 were interviewed and 7 were not able to be interviewed. Demographic characteristics of the parents, nurses and physicians are summarized in Tables 1 and 2.

Cases were recruited into the study when the mothers were at the following weeks of gestation: 21-21 6/7 (1); 22 – 22 6/7 (12); 23 – 23 6/7 (12); 24 – 24 6/7 (11); 25 – 25 6/7 (4). With one exception, for all cases, mothers were hospitalized because of cervical insufficiency, preterm labor, and/or premature rupture of membranes. A total of 46 infants were born, which included two sets of twins and two sets of triplets. Of these 46 infants, 7 were stillborn and 10 died within the duration of the study protocol, including two sets of twins and one set of triplets. For the 40 cases, the mothers gave birth at the following weeks of gestation: 22 – 22 6/7 (2); 23 – 23 6/7 (11); 24 – 24 6/7 (7); 25 – 25 6/7 (7); ≥26 (11); unable to obtain information from the medical records [mother gave birth at a non-IRB approved site] (2).

Categories of Nurse Behaviors: Parents and nurses both described several ways that nurses assisted parents surrounding decision making for their infants: (1) providing emotional support; (2) giving information, and (3) meeting the physical care needs of mothers, infants, and fathers. All of these behaviors helped to create the caring environment necessary for parents surrounding decision making. Physicians' description of the nurse behaviors was limited but focused on the way nurses provided emotional support and gave information. A summary of the behaviors as described by parents, nurses, and physicians is found in Table 3.

CALLOUT 2—For both parents and nurses, providing emotional support was the most commonly reported way that nurses assisted parents around decision making. Giving information and meeting the physical care needs were the other reported ways that nurses assisted parents. These categories were identified prenatally, postnatally and at the end of life by parents and nurses. However, depending on the type of interview (prenatal, postnatal and end of life) and the participant (parent, nurse or physician), particular categories were more salient. Furthermore, during the end-of-life interviews, parents, nurses, and physicians described the many ways that nurses provided emotional support to parents after the baby died. Nurses assisted parents to create meaningful memories, such as bathing and clothing their baby, and by gathering mementos, such as taking photographs and footprints. While providing this type of support is extremely important, the focus of this article is on decision making for life support, thus these data will not be presented here in detail.

Parent Description of the Nurse Behaviors: Providing emotional support. According to most of the mothers, nurses assisted them by providing emotional support. Fathers reported this finding also but to a lesser degree. Parents explained that nurses provided emotional and spiritual support by: (a) taking the time to listen, (b) being kind and comforting, (c) offering hope, and (d) giving spiritual support. Many parents described the importance of nurses taking the time to listen to what they were experiencing. Taking the time meant that nurses did not rush in and out, but rather were patient and spent time asking mothers how they were feeling. These behaviors were mainly described by parents during the mother's hospitalization prenatally and by a few parents in the NICU.

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Parents used several adjectives when they described how nurses were kind and comforting: nice, supportive, caring, and compassionate. Being kind to parents was perceived as being especially important because as one mother said, “parents are about to or could lose their baby. However, a few mothers described incidents where nurses were unkind, as illustrated by a mother’s description of an interaction prenatally when the mother was trying to sit up in bed slightly to minimize her difficulties with eating, “So she [nurse] says to me, are you not concerned about your baby’s life?... I’m like, how cruel of you....You know, I could have choked her.”

When nurses talked to parents, mothers in particular explained that nurses were often comforting in their words and actions. Mothers reported instances of nurses being available to them when they were crying. In other instances, nurses provided comfort, or according to one mother, treated her as her mother would have:

> Whenever I describe her (nurse), I describe her as a person who treated me like my mother would have; only the only difference is that she was professional about it.... Oh, very compassionate and yet professional, you know? She knew the right words to say.

Another mother referred to her prenatal conversations with nurses as “soothing” and said, “a lot of nurses have children, you know, they do not talk about their kids a lot, you know, they are very, they realize there is a situation here, and they are not trying to make you feel bad”. Parents often found nurses to be comforting surrounding end-of-life care for their infants. However, several mothers reported feeling like they were bothering the nurses. For example, one mother felt that, “a lot of nurses who do not want to be bothered they just there to do their job and that’s it.”

Both mothers and fathers reported that many nurses provided hope to them prenatally by believing that parents would get through the experience. Nurses relayed hope by sharing personal and professional stories. For example, nurses relayed stories of other mothers’ prolonged hospitalizations, which meant that the infant was not born at such an early gestation. One mother recounted a humorous story from the nurse:

> Some have given me some, you know, an anecdotes about yeah this one lady stayed. She stayed so long. She brought in her fax machine because she (laughs) she was so busy. You don’t have to worry about me bringing the fax machine in to do all my 900 pieces of activity...and so they helped in the sense that...You know, they have seen people.

It should be noted that in one case the use of a personal narrative was not helpful for the parents as it did not relay hope. In this case, a nurse talked about her personal experience of the death of her twins who were born prematurely. The father explained that while it was good to hear of others stories, it was not helpful to hear that the infants died.

A few parents described instances in which nurses provided them with spiritual support by praying with or for them, which parents perceived to be helpful. One father explained: “In fact, a couple of nurses came in and they said now it’s up to God, you have to pray. That’s really helpful for you, you know what I mean, it helps.”

Giving information. The majority of parents explained that nurses assisted them by giving them information. Nurses gave information by: (a) helping parents to understand the prognostic and other health information that the physician had given, (b) answering questions, (c) explaining the care that the mother and infant were receiving or expected to receive, and (d) providing information on the NICU or other resources. These behaviors

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were described by parents during the mother's hospitalization prenatally and were prominent during the postnatal interviews of parents during the infant's time in the NICU.

Many of the parents described the nurses as being knowledgeable and informative. Although, the nurses were not usually present when physicians or NNPs gave diagnostic and prognostic information about the mother and infant, the nurses were often the ones that parents turned to when they had questions. Nurses provided explanations so the information was more easily understood. According to one mother, "Well, the nurses I had were very...I mean they themselves knew a lot about stuff, you know like of the situation I was going through and if I wasn't sure of something, they would inform me of that and they would take time to go and try to figure, you know, try to answer my question themselves."

While the physicians and NNPs gave the diagnostic and prognostic information, it was often nurses who explained the actual day to day events regarding the ongoing care. Parents appreciated when nurses took the time to tell them about every procedure that was going on, for example, about the fetal heart monitor, or what was occurring in the delivery room. Postnatally, parents appreciated when nurses gave personalized information about their baby, such as comments about the infant's unique behavior. In addition to directly providing information, several mothers reported that nurses gave them a tour of the NICU or booklets related to prematurity.

The majority of parents favorably articulated how nurses provided information, but a few parents felt that the nurses were not giving them the information they needed. For example, one mother said that, "Yeah, some nurses you could ask them a question and they very blunt, you know, they don't have time...But then like you have some that will break it down to you." Postnatally, a father relayed that some nurses shared more information than others.

Meeting physical care needs. A smaller number of parents described ways that nurses met their needs as well as their infants' physical needs. Meeting the physical needs included: (a) making the mother comfortable, (b) responding promptly to a concern or request for care, (c) providing care to the infant in the NICU, and (c) showing concern for the father. Parents explained that these behaviors provided them with the comfort they needed at this stressful time and enabled them to focus on the decision making for their infant. The physical care that parents described included making the mother physically comfortable, such as repositioning her if she was on bedrest. A few parents, notably fathers, described how important it was when the nurse came promptly when called to care for the mother. In the postnatal interviews parents, more often mothers, turned their focus to the care the baby received from the nurses. Several parents positively described the care their babies received in the NICU. As one mother described, "She [nurse] is taking care of him as if he is her own."

Two mothers, during their end-of-life interviews, described talking to their nurse about their feelings that something was wrong. In one case, the mother believed that the nurse was the only one who listened to her concerns and acted on them. Another mother, however, did not think that the nurse listened to her. This mother reported that she repeatedly told the nurse about cramps, but said she was ignored. This mother went on to deliver her baby the same day who lived briefly.

A few fathers described how the nurses showed concern for their physical needs. For example, one father was hungry and the nurse took the time to get something for him to eat, "She [nurse] was trying to give me, like, some, she was trying to feed me, but I'm diabetic, so, so she was trying to give me, diet Jello and juices and, everything. So she looked out for me." Nurse Description of their Behaviors

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Providing emotional support. Most nurses reported that they assisted parents by providing emotional support. Nurses provided emotional support by: (a) taking the time to listen, (b) forming a bond with the mother, (c) being nonjudgmental of the parent lifestyle or decision choices, (d) offering hope, and (e) giving spiritual support. These behaviors helped mothers get through the emotionally charged nature of their experience, and were done to decrease their stress and to help them comprehend all of the information they needed in order to make decisions. These nurse behaviors were especially important prenatally given the difficulty many of the mothers expressed regarding in-patient hospitalization and prolonged bedrest. Nurses also described these behaviors postnatally and at the end of life. One nurse explained how essential emotional support was at the end of life. She said," You have to really, really support the parents."

Many of the nurses described providing support by taking the time to listen to the mother, assess her emotional state, and validate their feelings. One nurse said:

> Mostly I was there to listen to what she was feeling.... I mostly offered emotional support and you know validated the fact that she felt overwhelmed and that she was scared and unsure and we talked about how that was completely understandable and about how it was a difficult situation and you know she had every right to feel the way that she was feeling.

Some nurses felt that parents may feel comfortable talking to nurses and sharing their concerns regarding the decisions because of the amount of time nurses spend with parents in comparison to other members of the health care team. However, one nurse reported frustration with having to spend so much time with paperwork which took her away from supporting a mother. In addition, a few nurses relayed that their role was to provide emotional support without being judgmental to keep their own biases to themselves while working with the mothers. According to one nurse:

> I think one of the most important things that I can remember while I'm partnering someone through this experience is to keep my judgments out of the building. I think that the more neutral I can be and try to really help understand what this experience is like through their lens, helps me to be more compassionate and understanding and present."

A few nurses also explained how important it was for them to respect the parent's decisions surrounding end-of-life treatment. One nurse said, "So, I have to be supportive and that people are making these decisions are the ones that have to live with them."

Several nurses described how they offered hope and encouragement, as illustrated in a nurse's description of their scrapbook program.

> We have a scrapbook thing that we have on our unit for mothers who have been there for a long time and I found that is very interesting to look through because a lot of the mothers wrote their scrapbook page about their own story but they were also writing to other mothers that would be there after them, things like keep your eye on the prize and you know, I know how you feel, and just motivational type things and I thought the scrap booking was therapeutic both for the mothers who actually did it as they were working through their own feelings, but then to have the mothers who came later read it and see that someone else was going through a similar situation and they made it out the other side.

Only one nurse described how she provided spiritual support. Although this nurse did not provide much detail about this component of support, she did indicate that she assisted parents and their family members to find their inner spiritual strength.

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Giving information. Nearly every nurse described giving information as an important component of their interactions with parents who were faced with critical decisions. Giving information included: (a) helping parents to understand the prognostic and other health information that the physician had given, (b) answering questions, (c) explaining the care that the mother and infant were receiving or expected to receive, and (d) providing information on the NICU. These behaviors were described by nurses during the mother's hospitalization prenatally as well as postnatally and at the end of life when the babies were in the NICU. In the NICU, the role of the NNP in giving prognostic and diagnostic information depended on the collaborating neonatologist. One NNP explained how she was the person to inform the mother about her infant's deteriorating condition at the end of life. She said:

> I went in and talked to her and I said that the baby was really doing poorly and I didn't think he was going to survive a much longer and did she want me to call a chaplain, or, you know did she want the baby baptized, because I said, listen I think the baby is probably not going to live very much longer.

A majority of nurses viewed their role as assessing parents' understanding of the situation and then helping them to understand the information they were being given by physicians. Nurses described themselves as interpreters between parents and physicians. One nurse said:

> I think the best way that a bedside nurse can help a patient and family is to be in on as many conversations as you can possibly be in from the various team members. Because I think that any human being who is overwhelmed, whether they're immature at 18 or not, they have a really hard time kind of navigating the sea of information they're getting. And when language is different, you know, each discipline kind of has their own vocabulary. You know, I think my belief as a bedside nurse that I kind of, that I have the potential to kind of be the anchor. And I think that my role, the role that I've stepped into is to try to repeat some of what I've heard other people say and to try to explain how, OB/GYN said it this way, but the neonatologist said it this way, but they're really kind of saying the same thing. It's almost kind of like they need an interpreter.

Another nurse explained the interplay between providing emotional support and information. She said:

> Provide the information and listen to her questions and be sure she understood. Because a lot of times when you get them they are so overwhelmed, they can't take it in. They need a little time to take all this in....So, I think my goal is to provide a comfortable environment where their anxieties decreased and they can listen.

Several nurses described the critical importance of answering parents' questions, or referring them to the person who can best address their concerns. Sometimes that meant asking the physician or other members of the health care team to go back and talk to parents. Nurses also described how they explained in detail the current treatment plan for the mother and infant and also what to anticipate, for example, during the birth of the infant. A few other nurses described giving information by taking parents on a prenatal tour of the NICU.

Meeting physical care needs. Only a few nurses described ways that they met the physical needs of the mother and infant by making both comfortable. However, for these nurses, meeting the physical care needs was an important component of the way they supported the mothers. One nurse in particular who worked nights viewed physical comfort as an important component of how she cared for mothers. She said:

> I think things are different at night, because I think, our goal at this time is to kind of diffuse their anxiety. There are less people around, you want to try to get them

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> comfortable and quiet and see if there is anyway they can... I know it sounds silly, but to sleep.

Physician Description of Nurse Behaviors: The physician descriptions of the ways that nurses assisted parents surrounding decision making were limited. A number of physicians described how the nurses were there to provide emotional support and assist them to understand information. According to several physicians, nurses provided emotional support by talking to parents and just "supporting them". One physician even described how nurses offered to travel to a family's home to bring a mother to the NICU because she had no way to get to the hospital when the infant was going to be removed from ventilatory assistance.

Several physicians explained that it was helpful for the nurse to be present in the room when they talked to the parents. This approach enabled the nurse to understand the situation, reinforce what was said, and answer questions from the parents at a later time. One physician said:

> But I like when I do enter antepartum rounds and when I am on service and when I am the attending in charge, that a nurse for the patient is in the room when we're having the discussion so that they can reinforce what we have said or talked about.

Discussion: Parents reported that nurses played a very important role as they were struggling to understand information and make critical decisions. This finding is similar to other research (Kowalski et al., 2006; McHaffie, 2001; Wocial, 2000). In addition, parents and nurses reported similar nurse behaviors, which suggests that both have similar expectations for the role of nurses. While the same degree of comparison cannot be made with the physicians' reports because of limited data, these seem to be similar. Our findings indicate that the nurse's role in assisting parents with decision making is complex. By providing emotional support, information and meeting physical care needs, nurses create the context which both prepares and allows parents to make life support decisions for themselves and their infants.

CALLOUT 3—It is noteworthy, that the most frequently reported category in this study was providing emotional support. Our findings support previous research that indicates that nurses create a supportive environment which, in turn, may impact parent's abilities to make life support decisions, including at the end of life (McHaffie, 2001; Wocial, 2000). This context of caring facilitated largely by nursing behaviors enables parents to understand information and make decisions (Wocial). According to the parents in our study, nurses fostered a positive environment by talking and listening to them, being kind, believing the mother, being hopeful, and meeting physical needs. These behaviors were also important at the end of life once they had made the decision to withdraw life sustaining treatment.

Once the infant is born, parents often rely solely on providers to help them make decisions and to supply them with all of the information they need in order to make informed choices about their infant's care (Kowalski et al., 2006; Wocial, 2000). This study reifies previous findings that nurses are often the ones to provide the parents with understandable information, i.e., translating the medical information so parents can understand it (Kowalski et al., 2006; McHaffie, 2001; Monterosso et al., 2005). In particular, the nurses helped parents to understand difficult medical information as well as keep them informed about all of the procedures taking place. Nurses also spent time answering parent's questions and providing them referrals to someone else when they were unable to answer questions.

The findings in this study provide specific examples of the broad categories of support (information, advice, and emotional, instrumental and financial support) described in the

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Ottawa Decision Support Framework. However, upon completion of the data analysis many of the specific behaviors that were reported appeared to be closely related to Swanson's middle range theory of caring (Swanson, 1993). This theory of caring is comprised of five caring processes: maintaining belief, knowing, being with, doing for, and enabling (Swanson, 1993). In this study, the data illustrated the specific ways that nurses in this study enacted each of the five caring processes. For example, according to Swanson (1993), the caring process of "maintaining belief" includes offering a hope-filled attitude. In the research reported here, offering hope was one of the ways that nurses assisted parents. Thus, while this was not an aim of the research, the findings generated from this research lend further support to the usefulness of this theory.

Implications for Practice and Research: It is clear that nurses provide valuable decision support for parents regarding decision making for their extremely premature infants. The nurse's role in supporting parents during decision making is important for several reasons. First, the nursing perspective is unique. Nurses understand both the medical ramifications of these decisions and are often able to get to know the patient and family due to their frequent interactions with them. Second, nurses set the context of the parent's experience in the NICU and advocate for the infant and family.

Our findings provide specific examples of how nurses can support parents. First, it is essential for nurses to recognize the importance of emotional support and enact the behaviors described in this study and in previous research. Specifically, while nurses and parents may not articulate nurses' explicit involvement in medical decision making, nurses do create a necessary context in which parents can make decisions. Rushton (2005) refers to this as the "atmosphere of care". According to Rushton, nurses are in a prime position to engage with patients and by being fully present with families nurses show the patient and family that they are cared for.

In addition to creating an atmosphere of care, the findings from this study illustrate the importance of giving information and communication. However, communication extends beyond patients and nurses. Communication between physicians and nurses, and among nurses on the different obstetric units is essential to keep parents accurately informed of the mother's condition, the treatment plan, and decision options. Participating in rounds, being present when physicians counsel the mothers, and documenting those conversations help nurses in providing continuity of care. Staffing is also very important, in that the parents appreciated when the nurse could spend time with them and not rush in and out of the room.

Due to their role in alleviating stress and anxiety for mother's on bedrest (Maloni & Kutil, 2000; Price et al., 2007; Richter et al., 2007), nurses who care for mothers with a threatened preterm delivery, can actually play a critical role in helping parents make important medical decisions. However, further research is needed to examine the role of the nurse more specifically. It will be important to assess exactly what parents' needs are during the conversations that occur surrounding life support decisions for their infants, and to determine the importance of the nursing role.

The nurse role was only one aspect of this study in decision making so the amount of data are limited, especially for the physicians. Also, the diversity of the sample in this study is limited with few Caucasian parents, and the participants were not selected randomly. Furthermore, these findings show support for the caring processes identified by Swanson (1993). In the future, investigators could explore more specific ways that nurses can enact the caring processes so that ultimately Swanson's caring theory can be used in future intervention research.

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Conclusion: Nurses play an important role in assisting parents surrounding decision making for life support for their extremely premature infant. By providing parents with quality care, support, and information, nurses create the context that is needed in order to facilitate and support parental decision making.

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Table 1

Characteristics of the Parents (n = 54)

Characteristic	M (SD)
Age at Interview	29.02 (7.28)
Years of Education	12.84 (4.09)

	n	%
Race		
American Indian/ Alaskan Native	1	1.9
Asian	1	1.9
Black/ African American	31	57.4
Hispanic/ Latino	15	27.8
White	5	9.3
Other	1	1.9
Marital status		
Married	20	37.0
Single – Living with Partner	15	27.8
Single	16	29.6
Divorced	2	3.7
Other	1	1.9
Religion		
Roman Catholic	15	27.8
Christian, not Catholic	30	55.6
Not Reported/ Other	9	16.7
Income		
< $5,000	5	9.3
$5,001-10,000	5	9.3
$10,001-24,999	3	5.7
$25,000-29,999	6	11.1
$30,000-50,000	11	20.4
$50,001-70,000	7	13.0
$70,000-90,000	2	3.7
> $90,000	8	14.8
Not reported	7	13.0

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Table 2

Characteristics of Health Care Providers

	Nurse and NNP (n=29)	Physician (n=42)
Characteristic	**M (SD)**	**M (SD)**
Age at Interview	39.41 (9.98)	41.57 (10.55)
Years in Profession	15.57 (9.70)	15.60 (11.15)

	n	%	n	%
Race				
American Indian/ Alaskan Native	0	0	1	2.4
Asian	2	6.9	15	35.7
Black/ African American	4	13.8	4	9.5
Hispanic or Latino	0	0	3	7.1
White	21	72.4	18	42.9
Other	1	3.4	1	2.4
Missing	1	3.4	0	0
Gender				
Female	29	100	24	57.1
Male	0	0	18	42.9
Religion				
Roman Catholic	13	44.8	15	35.7
Christian, not Catholic	9	31.0	8	19.0
Hindu	0	0	6	14.3
Jewish	0	0	5	11.9
Muslim	0	0	2	4.8
Buddhist	2	6.9	0	0
Not Reported/ Other	5	17.2	6	14.3

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Table 3

Nurse Behaviors

Nurse Behaviors	Parent Reports	Nurse Reports	Physician Reports
Emotional Support	Listening	Listening	Talking
	Being kind and comforting	Forming a bond	Supporting
	Offering hope	Being kind and nonjudgmental	
	Giving spiritual support	Offering hope	
		Giving spiritual support	
Giving Information	Helping parents understand health information	Helping parents understand health information	Helping parents understand health information
	Answering questions	Answering questions	
	Explaining care	Explaining care	
	Providing information	Providing information	
Physical Care	Making mother comfortable	Making mother and infant comfortable	No instances described
	Responding promptly		
	Providing care to the infant		
	Showing concern for the father		